

Alzheimer's & Dementia Resource Book



COMMUNITY FIRST
SOLUTIONS

-A Not-For-Profit Network Since 1918-

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Section 1: Taking Care of You

The most important thing to remember when caring for a loved one with dementia, is that you must first take care of you. Many caregivers put their own lives on hold in order to care for someone else. In order to provide care for someone else, you must take care of your own well-being first and foremost.

This section contains a detailed explanation of how to identify burnout and stress in yourself. There are ways to receive support and access care outside of your own home. Too much stress can be damaging to both the caregiver and the person with dementia. Respite care is an option, and it is ok to take a break from your duties.

**Another important idea to note, is that those caring for persons with dementia should first understand the disease in its entirety. This resource book is a great place to start.*

Stress & Burnout

Some symptoms to note when caregivers become stressed include: anger, depression, high levels of anxiety, sleeplessness, withdrawal, issues with physical health, weight gain or loss, irritability.

Some tips to deal with these symptoms include:

Take Care Of Yourself By:

- Exercising
- Eating healthy
- Giving yourself more credit
- Getting plenty of rest

Seek Available Alternatives

Respite care

Adult day centers: know where they are located in your area

Family members: ask for a day off from caregiving

Home health care

Become Educated

Learn how to handle behaviors

Know how to communicate

Seek out community resources

Know how the disease will progress in the future

Understand

It is normal to feel overwhelmed when caring for someone with dementia. Know that you are doing the best that you can do, and you have nothing to feel guilty for. If you experience burnout, seek help immediately. It is important to receive support and to know the resources that are available for you in your community.

Support

Support is available for caregivers in the way of **support groups**.

Community First Solutions offers an Alzheimer's and Dementia Support Group that meets the third Tuesday of every month at Berkeley Square. This is an opportunity to meet and discuss your thoughts and concerns with others who are experiencing the same stressors.

Be sure not to isolate yourself. If you are not comfortable with attending a support group, connect with friends and family members who may understand what you are experiencing. It is important to know that you are not going through this process alone.

Respite Care

Respite care is defined by Macmillan Dictionary as “the temporary care of someone who is ill, old, or has a physical or mental problem, either at home or in a special hospital, in order to allow the person who usually looks after them to have a rest”.

This is an outlet for caregivers to receive a small break from their duties while also ensuring that your loved one is receiving care from medical professionals. Some hospitals and nursing homes offer these short-term stays of a few days to a few weeks.

Remember, it is ok to take a break. Your well-being is important.

Understand the Disease

In order to provide the best possible care, it is important that you fully understand dementia. The next section will outline the disease, signs and symptoms, and the progression.



Section 2:

Understanding Dementia

The term “dementia” is used to describe a group of disorders that affect memory and the brain. Dementia includes a loss of intellectual function that may include reasoning, judgment, thinking, and remembering. This loss affects personality, behavior, and mental function, and those who are diagnosed with this condition will have severe changes in their daily functioning. Many people confuse Alzheimer’s Disease with dementia, and they believe these two terms are synonymous. The truth is in fact that Alzheimer’s Disease is a type of dementia, and according to the Alzheimer’s Association, it accounts for 60 to 80 percent of all dementia cases.

Types of Dementia

- Alzheimer’s Disease
- Vascular Dementia
- Dementia with Lewy Bodies
- Frontotemporal Lobe Dementia
- Creutzfeldt-Jakob Disease
- Parkinson’s Disease
- Huntington’s Disease

**Talk to a doctor about signs and symptoms that may affect your diagnosis*

Caregivers should be sure to note all signs and symptoms that they notice, in order to best receive the correct diagnosis and treatment. Be sure to note change in behaviors or pattern of daily living.

Alzheimer's Disease

Alzheimer's is the most common type of dementia, and it affects over 5 million Americans. Alzheimer's is a disease of the brain that destroys neurons. These neurons are responsible for the thinking, learning, memory, sensory, and muscle movements that we use every day. Without these neurons, the brain of a person with Alzheimer's can no longer perform these tasks.

There is still much that is unknown about Alzheimer's Disease, but progress is being made in the way of science in the area of the brain. Scientists believe that the brain may become damaged long before symptoms even begin to appear.

Warning Signs

One of the most common signs of dementia is trouble managing bills and budget in the household.

Other noticeable signs to look out for include:

- Memory changes
- Confusing time and place
- Changes in personality
- Misplacing things
- Withdrawal
- Losing track of date or season
- Difficulty holding a conversation
- Frustration when trying to remember things

Stages of the Disease


It is important to note that no two cases of dementia are the same. Each situation is different and the progression of the disease greatly varies. Stages are used to describe a possible reference for families to understand what may be coming next, and how to prepare for the future.

Early Stage- Mild

- Driving may become impaired
- Confusion when in familiar places
- Begins to isolate themselves
- Making bad decisions
- Easily upset
- Forgetful of daily routine

Middle Stage – Moderate

- Shorter attention span
- Restlessness
- Repetitive statements
- Repetitive movements
- Becomes suspicious or paranoid
- May begin hallucinating
- Problems recognizing loved ones
- Refusal to bathe
- Forgetting to groom
- Need more supervision



Stages and progression vary greatly from person to person. Take note of all changes in behavior and personality in order to best communicate this to doctor. Make necessary changes to living style and location as the disease progresses. Be sure your loved one is receiving enough care if they are to remain at home.

Late Stage- Severe

- Loss of weight
- Refusal to eat
- No self-care
- Inability to control bowel and bladder
- Swallowing difficulties
- Sleeping more often than not
- Susceptibility to illness due to weakened immune system
- Inability to communicate

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Section 3:

Continuing Communication

As the disease reaches later stages, it is often difficult to communicate with your loved one. The important thing to remember is that even though this person may not remember who you are, you being there is more meaningful than anything else. Oftentimes family members become frustrated and hurt that their loved one does not remember who they are, so they stop visiting. This section will give you tips and support on better ways to communicate, and ways to make your visits more meaningful.

Tips to Communicate

The first thing to remember when communicating with someone with dementia is to be patient and be as understanding as possible. While each case differs, it is common that your loved one may not remember you and may not be able to hold a conversation.

Your loved one will greatly benefit from continued conversation, even without responding.

- Approach by introducing yourself by name first and association second. “Hello I am Mary”. If they seem confused, continue with “Mary, your daughter. How are you today dad?”
- Be sure to **avoid open ended questions** that may cause confusion
- **Avoid arguments at all cost.** If an argument arises, or your loved one becomes agitated do your best to switch the conversation. Walk away for a minute and return.
- **Have patience**
- **Avoid correcting;** Do not tell your loved one that they are wrong or confused, try to state the correct clarification instead.
- **Show interest** in what they are talking about. Do your best to find meaning in the words they say. Even though it may not make sense, respond in the best way you can.
- **Use short, simple words and phrases;** avoid long drawn out stories
- Talk slowly and clearly

- Ask one question at a time, and allow time for them to answer
- Avoid negatives, make them positive; negatives may lead to agitation. Instead of saying “you can’t go there” say “let’s go here”

If your loved one does not remember much from the present, connect to things that they do remember. Oftentimes persons with dementia will remember events, hobbies, or things they enjoyed in younger years. Focus on what they remember, and find as much meaning in the conversation as possible.

**Your continued visits and communication are beneficial to the person’s well-being*

Meaningful Visits

If your loved one resides in a nursing home, or is spending time in a hospital, visits are very important to continue. Often these residents have human contact with only nursing staff, and may become very lonely. Uses the Tips to Communicate above to make your conversations more meaningful, and try to visit as often as possible. This section will contain tips of activities and ways to spend time with your loved one more appropriately.

- Bring pictures, of family members who could not attend the visit, or of loved ones in the family in order to keep your loved one connected to things that are happening. Explain who each family member is in the pictures if they become confused.
- If possible, take the resident out of the facility on a walk or ride to show them that they are not trapped inside. They often need a connection to the outside world.
- Enjoy puzzles, board games, card games with your loved one. Be lenient with rules and way of play.
- Assist your loved one with grooming, fix hair or paint nails.
- Bring young kids to visit, often older persons enjoy watching little one’s play. This is something they are able to connect to, even if they are unsure who the child or baby is.
- If possible, bring small dogs to visit. Animals have a way of bringing happiness to everyone. If your loved one once had a pet, this may connect them to those memories.
- Bring a meal to sit down and enjoy with your loved one. Often these residents eat in larger dining rooms with little to no communication with other residents. Bring favorite restaurant/food/dessert.

- If allowed by the facility, take loved one out for holidays. This will be a very big step for someone with dementia, but they may enjoy the time around family. If necessary, make the visit short and sweet so they do not become too overwhelmed. Be sure to warn all family members of the situation beforehand.
- Participate in facility activities with your loved one.

**Remember to always check with facility in advance before bringing food or taking resident out of building. Resident may be on a special diet, or need medication before or after outside visit. Check resident in and out at the front desk.*

Understanding Behavior Changes

Dementia can cause some changes in a person's behavior that may be noticed in the form of yelling, name calling, cursing, hitting, kicking, biting, etc. It is important to note that not all person's with dementia will exhibit these behaviors. This section will outline why these behaviors may be happening, and what you can do to understand their meaning.

If your loved one has trouble with verbal communication, these ways of acting out could mean that they are trying to express something to you. Often if someone is in pain or experiencing discomfort, they are unable to say it.

Other **causes** of this behavior may include:

- Side effects of medication
- Being overstimulated in a loud environment
- Being in an unfamiliar location
- Feeling angry or agitated with their confusion
- Having to go to the bathroom
- Feeling hungry or thirsty
- Feeling tired

Here are some ways in which you can **respond** to these behaviors:

- Take note of what happened before the behavior
 - Was he/she introduced to a new situation or environment?
 - Where did this behavior happen?
 - Was there an unfamiliar person around?
- Ask the nursing staff if this behavior is new
- Offer a snack or drink of water
- Ask nursing staff to assist resident to the bathroom
- Engage in a new activity
- Do your best to respond positively

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Section 4: **Caregiving Tips**

This section is for those caring for a loved one with dementia in their home. Caregiving is the most challenging but rewarding job that you will ever have. The first thing to do when providing care, is to remember to take care of yourself first. Section 1 of this book will teach you ways to do this. The next important thing to remember is that you must be educated about dementia. In order to provide the best possible care, you will need to know what to expect and how to handle different circumstances that may arise. Be sure you have a stable support system to turn to when things become stressful.

Things to Remember

- You must take time for your own life
- Do not put your own needs on hold
- Ask for and accept any help offered
- You are doing the best that you can
- There are resources available for extra support
- Take life one day at a time

Caring for a loved one at home may become a full time job depending on the needs of the individual. There are many things to take into consideration when providing care

Proving Care Needs

- Encourage food and liquid intake
 - Provide nutritious meals and plenty of milk and water
 - Monitor weight
- Maintain healthy skin
 - Shower regularly
 - Keep skin dry
 - Watch for pressure sores

- Keep up with bowel and bladder functioning
 - Make toileting program to keep continence
 - Monitor frequency of bowel movements
- Recognize pain
 - Look for nonverbal signs of pain
 - Note any behavior changes
- Continue physical activity
 - Walk as much as possible
 - Encourage therapy with small weights
- Visit the Doctor regularly
 - Alert doctor of any changes
- Maintain a safe environment
 - Avoid stairs if possible
 - Remove rugs and tripping hazards
 - Install rails and grab bars where necessary
 - Monitor use of appliances that could be dangerous
- Encourage continued contribution
 - Allow to do own activities as capable
 - Assist minimally with dressing, bathing, and eating
- Monitor mouth care
 - Brush teeth after all meals
 - Soak dentures at night if necessary
- Maintain daily routine
 - Keep routine as organized as possible
 - Write down schedule if necessary
- Monitor medications

Resources

For those living with dementia and their loved ones, meeting everyday needs can seem impossible. Community First Solutions offers a variety of programs to not only meet these basic needs, but to help clients remain independent and happy; improving quality of life for all.

Alzheimer's Support Group Meeting

3rd Tuesday of every month Berkeley Square Haith Dining Room 7 pm – 9 pm

Bridges Rehab at Home: The Memory Care Program

A team of clinicians use a blend of compassion and training to work with clients who face the challenges of cognitive and memory deficits. Building effective communication methods and intervention strategies, highly trained speech pathologist clinicians work with patients and their loved ones to encourage memory recall and provide caring support. By working with clients in their homes, Bridges provides a pathway to increased independence and quality of life.

Colonial at Home

Caring for a home, preparing meals, and managing everyday tasks can be difficult for any older adult. When facing cognitive and memory recall deficits, these activities can become more difficult to complete. Colonial at Home caregivers provide an array of support services, helping keep you or a loved one independent, thriving, and happy at home.

Independent Living Assistance (ILA)

Caring ILA staff support the independence of older adults living with dementia by understanding and managing each client's finances, health insurance, and schedule.

Inpatient Dementia Care

A familiar, homelike setting with personalized programs that are designed to address each resident's special needs is vital to individuals living with memory recall deficits. Highly skilled caregivers and comfortable amenities ensure a supportive community that is safe and free from outside distractions. Family members and residents can relax and enjoy quality time together, knowing that all needs are being met with the highest level of care.

Our Health & Special Care Wings Provide:

- Private, spacious rooms
- 24-hour skilled professional nursing care
- Secure courtyards for safe, therapeutic walks
- Intergenerational opportunities through the Colonial Schools
- Housekeeping and laundry services
- Delicious meals prepared by our expert culinary team
- Transportation
- Rewarding and stimulating activity programs
- Short and long-term care options

References

Alzheimer's Association caregiver notebook (2009). Des Moines, Iowa: Meredith Corporation.

Alzheimer's Association. Retrieved November 27, 2016, from www.alz.org

Macmillan Online Dictionary. Retrieved November 26, 2016, from <http://www.macmillandictionaries.com/dictionary-online/>

Medline Plus. Retrieved November 27, 2016, from <https://medlineplus.gov/dementia.html>